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Improving the epilepsy service: the role of the specialist nurse

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There is currently a wide variation in the level of service provided for patients with epilepsy across the UK. Evidence is becoming available to suggest that improvements in local service provision may be achieved through the intervention of a specialist nurse. Using practical examples, this article explores the roles of the epilepsy specialist nurse, and examines how they may benefit patients and improve services. Functions such as liaison, patient assessment and management, counselling, provision of information, education, and audit are considered. It is hoped that the improved co-ordination and management of epilepsy services, that is achieved through specialist nurse intervention, will lead to improved patient outcomes and increased cost-effectiveness.

Key words: epilepsy; specialist nurse; service provision; UK.

INTRODUCTION

Epilepsy is the most common, serious neurological disorder, affecting over 300 000 people in the UK[1–3]. Despite the large number of individuals who suffer from this condition, recent studies indicate a wide variation in the level of service provided for patients by the National Health Service[1,3]. Even taking into account advances in diagnostic imaging techniques and the large increase in the number of drug therapies available, over 40% of patients continue to experience seizures and many do not receive appropriate care, information and advice about their epilepsy[1]. A number of regional health authorities are attempting to address these issues by developing structured epilepsy services dedicated towards patient management. The emerging success of many of these contemporary services can be accredited, in part, to the implementation of specialist nurses, who are key players in developing and co-ordinating the service[4]. With over 90 epilepsy specialist nurses (ESN) currently working in the UK (Epilepsy Specialist Nurse Association 1999, personal communication), their value as an important and effective, albeit scarce, resource is becoming increasingly apparent. This article will explore the various roles of the ESN and examine how they contribute towards improving service provision.

THE UK EPILEPSY SERVICE AND SPECIALIST NURSES

UK service provision

The need for improved epilepsy services in the UK was highlighted 6 years ago in an *Epilepsy Needs* document, which was endorsed by the Department of Health[5]. However, a number of years later it is still evident that the level of service offered to patients varies considerably across the UK and that the service is often under-resourced. This fragmentation of epilepsy services has been documented through a recent national audit[3]. In carrying out this audit, 1212 questionnaires regarding local epilepsy services were sent to consultants in neurology, paediatrics and learning disabilities based in 340 acute and community trusts across the UK. Six hundred and twenty-eight com-

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pleted questionnaires were returned from 273 trusts (51.8% response rate). Applying selection criteria to eliminate duplicate responses from the same specialities within each hospital left a total of 461 valid questionnaires. The results from the study demonstrated sizeable discrepancies between the services available to patients across areas, with service provision in many regions being far from ideal. It was found that:

- forty per cent of patients had never been seen in a specialist epilepsy clinic;
- in many areas there were long waiting times for referral and investigation. Ten per cent of respondents recorded waiting times for epilepsy clinics of four months or over;
- over half of respondents did not have a specialist nurse in their area;
- many regions did not provide adequate patient information and advice, with 14% of respondents providing no information at all;
- seventy per cent of respondents had no contact with patient support organizations;
- there were poor links with primary care, with only one in ten respondents working to shared-care guidelines;
- clinical guidelines were used by only half of respondents;
- approximately half of all services had not been audited.

These results can be further substantiated by a number of smaller studies in which patients themselves were questioned about their perception of the service that they were receiving from either a general-practice setting or hospital-based clinic[6–8]. The feedback from the patients was that they wanted a better structure of care, more information and advice on their condition and medication, and more details on the impact that both the epilepsy and their medication might have on their way of life. Up to 70% of patients particularly wanted contact with an ESN[8].

Evidence for effectiveness of the epilepsy specialist nurse

Evidence is now becoming available to suggest that the appointment of an ESN can lead to improvements in the service offered to patients and in the way in which patients perceive their care. The strongest evidence for these claims comes from a randomized, controlled trial, which was undertaken to assess the feasibility and effectiveness of nurse-run epilepsy clinics in primary care[9]. This study involved 251 adult patients from six general practices in the South Thames region. The overall conclusions made from the investigation were that nurse-run clinics were feasible and well attended. There was a significant improvement in the level of advice recorded (drug therapy, treatment compliance and lifestyle issues) and ways in which drug management could be improved were identified in one-fifth of patients.

The results from this study are concordant with a number of other investigations in which the effectiveness of ESN intervention has been examined[4, 10–12]. One of the largest of these studies was designed to assess the effectiveness of a primary care-based ESN in providing epilepsy care[10]. In order to obtain this information, a follow-up questionnaire was sent to 574 adult patients, registered in 14 general practices in northwest Bristol. Patients in seven practices, who had had access to an ESN for one year, were compared with patients in seven practices who had not. It was found that patients who had had contact with an ESN were much more likely than control patients to have discussed most epilepsy topics with their GP and/or hospital doctors and were also significantly more likely to have categorized GP care as excellent. Similar results were obtained in another study in which the effectiveness of an ESN in primary care was investigated[11]. Based on before and after interviews with 50 adult patients in the South Thames region, who were either in remission or who had a low seizure frequency, it was found that the expectation regarding the usefulness of an ESN was high and that these expectations were not disappointed in practice. Patients identified a distinct contribution of the ESN in empathic listening, communication of information and advice and in improving the continuity of care.

Comparable improvements in satisfaction and patient management have also been reported in two qualitative reports on specialist nurse intervention[4, 12]. Through the establishment of a nurse specialist service in paediatric epilepsy, within The Royal Liverpool Children's Hospital, Alder Hey[12], it was found that nurse specialists contributed towards improved counselling, support and education of families, and reduced the frequency of medical reviews required. The authors of this paper suggest that an improved understanding of epilepsy (and its treatment) could lead indirectly to an improved quality of life for patients with epilepsy and their families. Finally, in Doncaster, the deployment of specialist liaison nurses within a district epilepsy service, has made an important advance in the quality of care offered to patients[4]. Through nurse intervention it has been possible to manage changes in medication at home, thereby reducing the need to attend clinic or see the GP. Improvements in the level of

counselling and support for patients and families were also noted.

In summary, the findings from these investigations suggest that the specialist nurse can make a significant contribution to the improvement of local epilepsy services.

THE ROLES OF THE EPILEPSY SPECIALIST NURSE

The ESN can have a number of roles within the epilepsy service, all of which contribute towards providing the patient with a holistic approach to disease management. The overall level of involvement of the ESN will depend on the organization of the local epilepsy service. Some of the many functions, which the ESN might have within the epilepsy service, are highlighted in Fig. 1.

Patient assessment and management

The ESN is often integrally involved in both the initial assessment of the patient and subsequent management of his/her condition. In order to provide continuity of care, the ESN will review the patient's condition, treatment and individual circumstances on a regular basis[13] and make recommendations for improvements to care. This could involve referral of the patient to another member of the care team. Any alterations in the patient's management programme, which may be implemented by the ESN, should be made according to local protocols and guidelines, with which the ESN would have been involved when developing[14]. Regular patient review by the ESN gives GPs and consultants more time to see new patients or existing patients with complications[4]. In circumstances where a switch in drug therapy is indicated, nurses are able to supervise these changes in medication, and thereby reduce the need for patients to see a neurologist or GP[4]. The nurse can also identify and advise on ways in which drug management may be improved[9]. In addition to providing continuity of care, this regular patient contact may allow a greater understanding of the patient and their epilepsy.

Counselling, advice, information and education

In terms of the individual patient and his/her carers, one of the key contributions that the ESN makes is in the provision of counselling, support, information and education[12]. Many patients find the diagnosis of epilepsy hard to come to terms with, but information provided by the ESN (both as advice and in the form of patient information leaflets) might help them to understand the diagnosis and deal with their condition in a positive manner. This type of information may include, for example[15–17]:

- general information about epilepsy and its causes;
- information on seizure types and what happens during a seizure;
- details of assessment and tests (including seizure description and history, EEG and neuroimaging);
- when and where to get help (including ESN and consultant contact details and availability, support groups and voluntary organizations);
- disease prognosis and future prospects;
- precipitating factors (such as stress, boredom, alcohol, fatigue, photosensitivity, hypoglycaemia, intercurrent illness and menstruation);
- lifestyle implications (on aspects such as employment, school, driving, safety, sport and leisure, relationships, pre-pregnancy planning and contraception);
- drug information (including seizure control, side effects, compliance, interactions, serum monitoring and other therapeutic approaches).

Certain subgroups of patient, such as women with epilepsy, may have additional needs and concerns. For example, women who are planning a pregnancy should receive pre-conception counselling and a thorough reassessment of their epilepsy[18]. In these patients, issues such as prenatal screening, teratogenicity, labour and childcare should be addressed. Given that some antiepileptic drugs (AEDs), such as phenytoin, phenobarbitone, valproate and carbamazepine, may be associated with an increased risk of foetal abnormalities[18], a switch in medication to one of the more contemporary AEDs (such as lamotrigine or gabapentin) may be indicated before the woman conceives. The ESN can play a central role in the rationalization of treatment in these patients and in supervising any changes in medication that may be required[4,9]. This is made easier as patients perceive the nurse as having more time to spend with them compared with consultants and GPs, finding them less threatening and more approachable[4].

The ESN also has a role in the continuing education and training of other healthcare professionals, students, teachers, employers, and care and voluntary organizations[4]. This may take the form of clinical attachments to an ESN or consultant, formal study days, training courses, or the establishment of resource libraries. One such educational initiative is the training

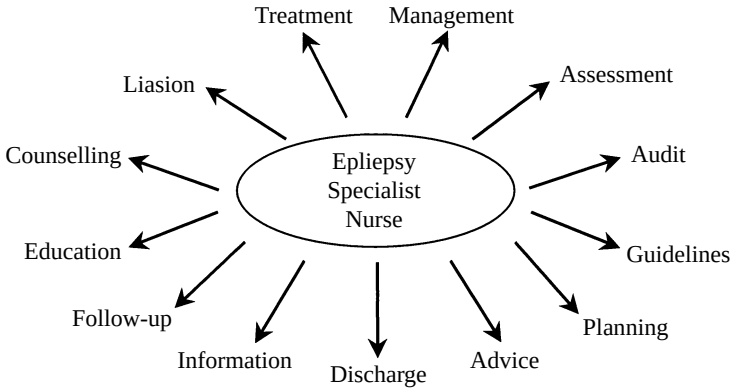

Fig. 1: The multiple roles of the epilepsy specialist nurse.

programme employed at Gogarburn Hospital, Edinburgh, to educate lay community care staff in general epilepsy awareness and in the administration of medication to adults with epilepsy and learning disabilities[19]. This course involves a teaching programme, given by the ESN and associate specialist in learning disability and epilepsy, in the basic aspects of learning disability and epilepsy and in the theoretical and practical aspects of drug administration during serial epileptic seizures and prolonged seizures. The training is formally assessed and, to date, nearly 800 people have successfully completed the course (Foley 1999, personal communication). It should be possible for ESNs and other medical specialists across the country to adapt and implement educational programmes, such as this, to meet their local requirements.

Liaison

Liaison between patients and primary and secondary care teams, to ensure well co-ordinated care, is another important function of the ESN[13]. With approximately 70% of people with epilepsy under the sole care of their GP[5], the hospital-based ESN, by forming links with primary care, may be able to access and mobilize large numbers of patients who have not been seen for some time. These patients may also not be receiving the most appropriate care and treatment for their epilepsy. In one recent study of 595 adult patients with epilepsy in general practice, it was found that 42% of patients had not seen a doctor about their epilepsy in the previous year, even though many of them were still experiencing seizures and drug-related side effects[8]. Significantly, patients receiving both primary and secondary care had the greatest needs and desire for better care. Given that many patients and doctors still accept a poor level of seizure control and reduced quality of life[20], ESN-facilitated liaison between primary and secondary care is becoming increasingly important.

In some regions, link-nurses (which may include community, practice and ward nurses, midwives and health visitors) are being set up to further facilitate this liaison. Link-nurses are nurses with a special interest in epilepsy that have received training in some of the basic aspects of epilepsy (general information, medication and quality of life issues). They work, in collaboration with the ESN, to educate, inform and support patients with epilepsy. One initiative developed by Edinburgh University NHS Trust and Lothian Health Board, is a basic training programme in epilepsy, which is run by ESNs for community nurses (Foley 1999, personal communication). The ultimate objective of this course is to allow community nurses to run their own epilepsy clinics in primary care (in conjunction with the ESN) and measure patient outcomes. This will hopefully promote shared care between the primary and secondary care teams.

In addition to liaising between primary and secondary care, ESNs may also provide links for patients, GPs and epilepsy care teams into schools, the patient's work place, voluntary groups, other health service departments, community and social services, learning disability teams and pharmacy services[4]. Fostering close links between these services and organizations is important for co-ordination of services, improving the patient's quality of life, and promoting general awareness of epilepsy and local services.

Adding value to the service

Regular audit of services is vital for improving both health and cost-effectiveness outcomes. In order to provide optimal services, each local epilepsy service should be regularly audited to identify areas of excellence and areas that could be improved[14]. Using standard data collection during regular patient review, the ESN can provide evidence of cost-effectiveness, quality and access to care.

As highlighted, the ESN can act in a number of different capacities. These multiple functions of the ESN will be of most benefit to patients and healthcare professionals when implemented in the context of a well-structured, well-resourced and fully co-ordinated epilepsy service. Three examples of regional services in which the ESN plays a key role are presented below.

THE SPECIALIST NURSE IN PRACTICE

Birmingham Brainwave women's clinic

This joint nurse- and consultant-led service originated 4 years ago, in the Queen Elizabeth Psychiatric Hospital, Birmingham, as a pre-conception counselling clinic. However, it soon became apparent that there was a need for a more comprehensive service involving all aspects of epilepsy management, with specific reference to women's issues. Epilepsy and some of the drugs used in its treatment can have a profound effect on many aspects of a woman's life, including sexual development, sexuality, menstruation, contraception, fertility, pregnancy, labour, the developing foetus, child care and the menopause[18]. These concerns are in addition to general considerations, such as seizure control and quality of life, and, as such, warrant extra attention.

The clinic operates an open referral policy, with referrals taken from GPs, obstetricians, midwives, neurologists, gynaecologists and ESNs. It is the aim of the clinic to review all new patients within 4–6 weeks of referral, with emergency patients seen within 2 weeks. Each patient undergoes initial review and assessment by an ESN, according to an agreed assessment protocol. This involves a full re-investigation of the patient's epilepsy, which includes physical screening, history and diagnostic tests, if appropriate. The initial assessment may last for up to $1\frac{1}{2}$ hours, with the consultant involved in the same consultation. Joint decisions are then made between the informed patient, the doctor and the ESN, based on the results of this assessment and patient wishes. In some cases it may be found that surgery or an alteration in drug therapy is necessary. Women are also offered pre-conception counselling, which is given by the ESN, over several visits to the clinic. During these visits women may be given advice and information on issues, such as[21]:

- effect of medication and epilepsy on fertility, contraception, sexuality and during pregnancy;
- need for and dose of folate supplement;
- safety issues;
- breast feeding and post-partum care;
- possible effects of the menstrual cycle on seizures;
- possible effects of the menopause on epilepsy.

The clinic also runs an active programme for teaching practice nurses and for providing advice about epilepsy audit in primary care[20]. Through these programmes close links have been forged with several general practices, with ESNs liaising directly with practice nurses with the aim of ensuring continuity of treatment. Close links with maternity, obstetrics/gynaecology and mental health units have also been established.

A recent audit of the service found evidence that pre-conception counselling was both effective and worthwhile[25]. The audit compared the outcome of pregnancies in women attending the clinic prior to conception with that of women who were already pregnant before attending the clinic. Pregnancy outcome data suggested that an active pre-conception policy, in particular increasing the number of women taking folate supplements before conception, might reduce foetal abnormalities. Pre-conception re-investigation also revealed a high proportion of previously undetected abnormalities that might have affected the outcome of pregnancy.

In order to continue providing a high quality of care and increase cost-effectiveness the Brainwave clinic is continually reviewed, taking into account new research data and feedback from patients.

Obstetric-epilepsy clinic, Jessop Hospital for Women

The joint obstetric–epilepsy clinic, which is held monthly at the Jessop Hospital for Women, is just one of many services provided by the Central Sheffield University Hospitals epilepsy liaison service. The clinic was initiated in 1994, after a need for improved epilepsy care was identified in women who were pregnant or who were planning a pregnancy (Mack 1999, personal communication).

In this clinic, the ESN works in conjunction with a neurologist, obstetrician and midwives to ensure the highest possible standard of care is provided for patients before, during and following pregnancy. Ideally, women are seen pre-pregnancy and during their pregnancy at 14 weeks (for booking), 20 weeks (after a foetal anomaly ultrasound scan) and each month thereafter until birth if necessary. An important role of the clinic is the review of the diagnosis of epilepsy and this is best undertaken prior to conception. First appointments with the ESN are usually undertaken at the time of the first clinic visit. During this appointment, and in subsequent visits, the ESN will review the patient's condition and medication and provide her with

pre-conception counselling and an individual management plan. The ESN also forms close links with each member of the care team (in primary, secondary and tertiary care), and provides open access to the service for continuing advice and support. Prescribing of AEDs by a nurse is undertaken according to a protocol agreed with local neurologists. Other roles include training and education in the health service and community, assistance with the audit, and advice on general epilepsy-related issues.

During a recent audit of the service, it was found that 36% of patients when assessed had not been adequately investigated for epilepsy and 26% of patients attending the clinic required changes in their medication during pregnancy. Over half of women had received no pre-conception counselling prior to attending the clinic and only 32% had been advised to take pre-conceptual folate supplements. It is therefore becoming evident that this combined obstetric–epilepsy clinic can provide an improved service to women in Sheffield who are pregnant or planning a pregnancy.

Lothian Primary Care NHS Trust learning disability epilepsy service

Lothian Primary Care NHS Trust learning disability epilepsy service is a joint medic- and nurse-run service, which is provided by a learning disabilities associate specialist and a specialist nurse in learning disability and epilepsy (Foley 1999, personal communication). The service was introduced to improve the standard of care offered to people with learning disabilities and epilepsy in Lothian. Historically, these patients have often received inadequate care and irregular treatment review despite their special needs[22]. However, Lothian Primary Care NHS Trust and Edinburgh University Hospitals NHS Trust have been working together to develop a framework to assess and support people with learning disabilities[23].

Clinics are held at five different health centres in Lothian, thereby reducing the need for patients to travel long distances to access a specialist opinion. All new referrals are reviewed initially by the specialist; however, the ESN can be involved from an early stage to help to consolidate the information and advice given at first consultation. As part of the patient's initial assessment the ESN will often carry out visits to homes, training and resource centres, and places of employment to gain a clear picture of the patient's condition and any special requirements that he/she may have. The ESN is then required to liaise with the patient's family and all service providers to discuss treatment options. Careful consideration of drug therapy is very important in people with learning disabilities and epilepsy because of the potential for long-term adverse reactions to treatment and the possible detrimental effects of some types of AED on already compromised cognitive function[24]. After initiation of treatment, the ESN is heavily involved in monitoring the patient's treatment and condition to ensure that optimal benefits of therapy are achieved.

The ESN also plays a lead role in educating carers in the home setting and is responsible for ensuring that they are aware of their responsibilities with regard to recording, compliance and adherence to prescribed treatment. This is particularly important for voluntary sector carers who may not fully understand the implications of epilepsy in people with learning disabilities. An additional responsibility of the ESN is to ensure that patients, carers and other healthcare professionals are kept up to date with any new and relevant findings, which could have implications for future therapy.

The role of ESN within this dedicated service is audited on a regular basis to ensure patient and carer satisfaction. It is expected that future audit will help to improve services and provide better access to these services for people with learning disabilities.

SUMMARY

The level of epilepsy service provision varies considerably across the UK. However, evidence is growing to suggest that ESN intervention can lead to significant benefits for patients and healthcare professionals. Through various functions, such as liaison and training, the ESN helps to improve the co-ordination and management of local services. In some regions, such as Birmingham, Sheffield and Lothian, this type of nurse-led service is already in place and working effectively. Ultimately, this should lead to better patient outcomes and a more cost-effective epilepsy service.

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